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ABSTRACT

Feelings and attitudes were investigated among family members with mentally ill relatives whose treatment delivery system was being "deinstitutionalized" or moved from hospital-based treatment to community-based treatment. Subjects (N=125) were interviewed at home by either mental health professionals or professional interviewers. Results indicated that: (1) family members felt embarrassment at having the former patient at home, but not an overwhelming sense of burden unless the patient's behavior was highly overtly symptomatic; (2) families without adult support were more likely to feel burdened; (3) normal routines tended to be disrupted most often when only one relative was present to cope with the former patient; and (4) parents tend to be the most accommodating when the former patient's behavior is judged "abnormal." (Author/HLM)

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The Cart Before the Horse: Families Coping with the Policy of Deinstitutionalization

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The Cart Before the Horse: Families
Coping with the Policy of Deinstitutionalization

Inadvertently, the families of the mentally ill have been thrust into a front line position in the nation's mental health delivery system. The 1960's policies for deinstitutionalization[1] have given rise to more rigorous legal safeguards for patient's rights, an interest by many states to get out of the mental health business, and the development of community-centered treatment programs (Backrach, 1976; Bassuk and Gerson, 1978). With these new arrangements, patients in the community are thought to be "better but not well" (Klerman, 1977). But with the shift from a hospital-based to a community-centered delivery system, families of the mentally ill are no longer exempt from sick-care functions. Increasingly, with brief hospitalization and patients[2] living in the community, if not at home, families are becoming involved in the long-range care of their psychiatrically disabled kin, and have been obliged to become facilitators of rehabilitation, if not de facto therapists (Vincent, 1967; Doll, Thompson and Lefton, 1976).

As progressive as it may be for families to assume a central role in their relative's health care team, the family's role in this treatment network may be causing serious stresses in the lives of those families who have had to assume some responsibility for the care and rehabilitation of their mentally ill relatives. The policy of brief hospitalization and returning the patient to the family has developed

in advance of knowledge concerning the effect of this practice on the family. If the family is obliged to provide the care-taking (custodial) and care-giving (therapeutic) settings for its psychiatrically disabled relatives, we need to know more about the degree to which the family is able or desires to take on these responsibilities (Vincent, 1967:24).

This paper examines how families cope with the potentially stressful situation of caring for their mentally ill relatives. Of specific interest are the variations in family burden which result from differences in family composition. Through an analysis of the relationship between family composition and objective and subjective burdens, namely those having to do with actual disruptions in the family's routines and those having to do with the family's affective response to the patient's presence, we hope to be able to delineate some of the major, albeit less visible consequences of deinstitutionalization.

The Concept of Family Burden

The adversities awaiting the mental patient's family on his return home have been a central research focus since the 1950s. The early concern, with the impact of the patient's hospitalization on family attitudes (Cumming and Cumming, 1957), found that there was some stigma, but it was less than expected (Freeman and Simmons, 1963; Rose, 1959). Other studies concentrated on the extent to which the mentally ill relative was considered dangerous.[3]

In recent years, there have been several efforts to conceptualize a more holistic, thorough understanding of the family's response to the mentally ill member's return home. Grad and Sansbury (1963) systema-

tically studied whether the trend toward caring for the patient in the community resulted in any costs to the family. Introducing the notion of "family burden," they found that with the former patient's return home there was indeed a drain on family life. Although a sense of burden was not the dominant reaction, a fifth of their families did report "a severe problem of management of one kind or another; either domestic routine of their households was upset, their social life and work interferred with, their health affected, or their incomes reduced" (1963:312).

Hoenig and Hamilton (1966) also studied these objective family burdens, and found over two-thirds of their families experiencing at least some form of burden. They reasoned, though, that there was another dimension to familial coping, a more "subjective" dimension to how families react. Separating the concept of family burden into an objective component and a subjective one, Hoenig and Hamilton defined the subjective dimension simply as "what the relatives themselves felt about the burden" (emphasis added, 1966:170). Nearly half of the families in their study also felt burdened, and nearly one out of ten families felt severely so.

A few other researchers (Bachrach, 1976; Brown et al., 1966; Williams et al., 1973) have begun to acknowledge the notion of family burden as critical. Most notable, Herz et al. (1976), who employed a similar objective/subjective conceptualization, reported findings most similar to those of Hoenig and Hamilton. Nonetheless, as Kreisman and Joy concluded in their 1974 review of the literature, "the affective component of the attitude toward the deviant and the sense of burden

that the family feels have still been inadequately treated" (1974:53). Family burden remains an uncharted corner of the community-based treatment movement.

In earlier reports on how families cope with mentally ill kin, we were able to take the Hoenig and Hamilton conceptualization a step further, specifying some of the affective dimensions of family burden (Doll, Thompson and Lefton, 1975, 1976: Thompson, Doll and Lefton, 1977). Rather than simply measuring subjective burden as a unidimensional feeling, we attempted to systematically define its dimensions. We found four analytically distinct feeling categories: Feelings of being trapped; unsympathetic feelings towards the mentally ill member; feeling distant and wishing to exclude; and a feeling that the former patient was a problem to have at home. These four dimensions reveal some of the affective stresses families experience in coping with a mentally ill member. Almost half of the families felt trapped, and roughly three-quarters were coping with ambivalent or contradictory feelings of sympathy and inclusion. Three of four families felt the former patient a problem. The intent in this current paper is to move our understanding of the burdened family a further step along, by specifying more precisely who experiences the burden. We now ask whether variations in family composition ease or exasperate family burden?

Methods

Study Group. The respondents were the relatives of persons who had been discharged from one of three state hospitals in Cleveland, Ohio, and returned to live with their families. Sampling for this study

was a two-tiered operation by necessity. Beginning with a population of all psychiatric patients[4] discharged to their families during the three months of October, 1972, through December, 1972, a random sample, stratified by hospital, was selected from the discharge rolls of each hospital. After eliminating cases who did not actually return to their families, the initial patient sample of 165 was reduced to 141 cases. From these, 127 relatives were interviewed, of which 125 were considered valid and useable interviews.

Data were collected through home interviews conducted by either mental health professionals or professional interviewers. Six months following discharge, an introductory letter was sent on the letterhead of the former patient's institution to both the former patient and the relative. Interviewers followed-up the letter with a phone call and made an interview appointment. We found no substantial reluctance to be interviewed. Approximately 90% of the relatives contacted were interviewed, which respresents a 75% return on the initial sample. Supplemental data were collected from hospital records on the patient's psychiatric condition and history.

All respondents were interviewed privately, without the presence of the former patient or other family members. Only the "key" relative was interviewed, that is, the person identified by the patient as the "significant other" in the hospital records. Obvious exceptions were made in cases in which the significant other no longer lived in the household or was consistently unavailable. In such cases the person defined as the most closely related relative living in the

household was interviewed.

The demographic characteristics of the sample of families are presented in Table 1. There were no significant differences among the three groups of relatives whose kin had been released from the different hospitals vis-a-vis relatives' characteristics. However, in terms of patient characteristics, despite random selection, patients released from the one long-term hospital were slightly older ($p < .10$) and more likely female ($p < .10$).

TABLE 1 ABOUT HERE

Measurement of the Dependent Variables. Investigations of family burden are relatively new. The issue was how to assess the ways in which former psychiatric patients affect their households and the extent to which they in fact did so. Toward this end, measures were constructed to (1) parallel as much as possible previous work, and (2) evaluate families' objective and subjective burdens.

Subjective burden was operationalized as the emotional costs the patient's presence and behavior had on his or her family. We were expressly interested in what relatives felt about having the former patient home. Attention was paid to the affective reactions, whether, as a result of the mentally ill member's illness, presence, and behavior, family members suffered a sense of burden. Studying subjective burden was not viewed as an inquiry into the objective facts, but a glimpse at the emotional fabric of the household long after the initial "crisis" of the patient returning home.

Measurement of the subjective burden borne by family members took

two directions. First, Freeman and Simmons' (1961, 1963) index of family members' embarrassment was selected as one measure. This Index of Shame contains five questions, each pertaining to a different form of the relative's shame. Specifically, the respondent was asked, "we would like to know which of the following have been problems since the former patient has been home:" (1) having him home makes family members less willing to invite people to the house, (2) having him home makes other family members nervous, (3) having him home may cause some neighbors to make remarks about the family, (4) family members sometimes avoid their friends because they are embarrassed, and (5) I see less of my relatives because I am ashamed. The respondent indicated a "yes" or "no" to each item. Thus, total scores can vary from zero to five, with zero and one indicating "no shame" and two or more embarrassed responses indicating "shame." The Cronback alpha coefficient (.86) suggests that the index is internally consistent.

Second, the four feelings Doll, Thompson and Lefton (1976) isolated as part of families' affective reaction were combined into an Index of Families' Sense of Burden. Guttman scaling showed the four feelings to be cumulative and showed that the index would accurately reflect the extent to which families feel burdened. The coefficient of reproducibility (.97) indicates that the following feelings, in order of increasing familial burden, form a strong, reliable index: (1) feeling that the former patient was a <u>problem</u> to have at home, (2) feeling <u>trapped</u>, (3) feeling <u>unsympathetic</u> towards the mentally ill member, and (4) feelings distant and wishing to <u>exclude</u> him from the family

circle. The index clearly suggests that families' sense of burden is a continuum with those families wishing to exclude their mentally ill member already feeling unsympathetic, trapped, and that he is a problem (Thompson, Doll and Lefton, 1977). Families' Sense of Burden was dictomized as "some burden" and "severe burden," with the latter indicating families who at least felt unsympathetic to the kin.

Objective burden was operationalized as the disruptions in family's everyday life which were attributed to the presence or behavior of the mentally ill member. We sought to assess the extent to which the functional tasks of family living, such as household routine, were adversely effected. Five relatively clear indicators of objective burden were obtained: families reporting a financial burden as a result of the patient returning home; relatives having to neglect their responsibilities to other family members; reporting an interruption of the family's normal way of life (e.g., eating and sleeping times); reporting that having the mentally ill member home is like having a 10-year-old child around; and, reporting that the former patient requires more supervision than would otherwise be necessary.

Unlike Hoenig and Hamilton's (1966) decision to define patients' abnormal behavior as another aspect of objective burden, on the grounds that "if such behavior was present more than occasionally, this would constitute some burdeon on the family (1966:167)," we decided that the patient's psychological functioning was more of an independent variable which likely causes family burden. Deviant behavior in and of itself is not an indicator of burden.[5]

In our attempt to describe the incidence of families' objective burden, and the extent to which it was reported, a Guttman scale was attempted. But that index was neither unidimensional nor cumulative (coefficient of scalability = .48). Given the five indicators do not form an index, to determine the incidence of families burdened in our sample, we merely identify the number of families reporting disruptions on the first three indicators. The respectively assess financial burden, role conflict, and disruption of the family's everyday routines.

Measurement of the Independent Variables. Three traditional measures of family composition and one measure of the former patient's psychiatric condition were used. Since we contend that the patient's condition probably causes family burden (rather than simply reflects it), "current" symptoms level was defined as the independent variable. A 22-item behavioral checklist (Freeman and Simmons, 1963; Angrist et al., 1968) was dichotomized as "low" (under four) and "high" symptoms, which roughly means "normal" and "abnormal" behavior, respectively.

With family composition perceived as a filter between the patient's presence and behavior and family burden, household size, type of familial relationship, and supportive network were considered conditioning variables. Household size was operationalized as: whether the family unit was composed of only the respondent and former patient; whether it had three or four members including the former patient; or, whether the household was larger than four members. Type of relationship was simply whether the family unit was conjugal, parental, or other more distant

relatives. Supportive network was a dichotomous category indicating whether there were other adults in the household besides the respondent. We reasoned that having other adults in the home--a "social support system" of some sort--should ease the strain. Much of the family literature, and for that matter the classic thrust of sociological thought, has argued the "irreplaceable comfort of others" (Bott, 1957; Durkheim, 1951; Nisbet, 1966).[6]

Findings

Subjective Burden. Many of the families interviewed felt the stresses of having to accommodate to their formerly hospitalized relative. Nearly half of the families felt embarrassed by the former patient being at home. Almost eight percent reported feeling a sense of burden.

TABLE 2 ABOUT HERE

As indicated in Table 2, both measures of subjective burden, the index of shame and the index of families' affective burden, were significantly related to the former patient's psychiatric condition. Since the patient's presence, or at least his psychiatric condition, leads to families feeling burdened, do variations in family composition ease or exasperate the burdens?

For the most part, troublesome behavior need not be as troubling when there are social supports. The data (Table 3) show that family composition does at times filter or modify the extent of burden. Generally, for family units of just the respondent and the patient, for those families

without another adult present to share the burden, and for the more distant family relationships (i.e., those without a marital or parental bond with the former patient), there were heavy emotional costs.

When the former patient's behavior was highly symptomatic, all of the respondents coping along with their seriously impaired kin member reported feeling a sense of burden. Add the sheer presence of another person, whether adult or child, and families' sense of burden or embarrassment was no longer significantly effected by the patient's behavior per se. Yet, adult supports do make a difference. Families without adult supports in the household were much more likely to be burdened by the former patient's psychiatric behaviors; they were more likely to report a sense of burden as well as embarrassment.

TABLE 3 ABOUT HERE

The data in Table 3 also suggest that spouses' feelings of burden are much more likely to be influenced by the former patient's psychiatric behaviors than are parents or other relatives.

When the former patient's psychiatric behavior is relatively "normal," and the question is simply families' feelings of being burdened by the mentally ill relative's presence, there are considerable differences in what families are more likely to <u>not</u> feel the stress. Family composition eases as well as exasperates the sense of burden and embarrassment. Spouses were significantly less embarrassed and less frequently reported a sense of burden. The same pattern applies to families without adult supports present and family units of just the respondent and the former patient.

In sum, when the patient's psychiatric behaviors were judged in the "abnormal" range, the more people present in the family setting the greater the ease in coping and the less likely are families to report a feeling of being burdened. But, when the patient's psychiatric behaviors can be judged relatively "normal," the more people present in the family setting the greater the burden of coping. This, it would seem that, family composition differentially filters: when the mentally ill relative returns home and behaves in a "normal" fashion, the more complex the family network or the more distant the familial bond, the more likely the family unit will sense the burden of another member. However, when the mentally ill relative returns home and behaves in an "abnormal" fashion, the smaller families and those without adult supports are more likely to be overwhelmed.

Objective Burden. Generally, a third of the families sampled found their daily lives disrupted by their mentally ill relative's return home. The less the former patient's symptoms were under control, the more likely was he to be an objective burden (Table 2).

TABLE 4 ABOUT HERE

The probability of burden is greatest in the family unit where the respondent is coping with the former patient alone; in households where there are no other adults; and, in the more distant family relationships (Table 4). For example, 92 percent of the respondents coping by themselves with psychiatrically impaired kin had their normal routines upset, compared to fewer than three-quarters of the larger family units. That three times as many respondents coping by themselves also find

kin with "normal" behavior disrupting strongly suggests their vulnerability.

Similarly, those family respondents without other adult supports in the household were more likely to report having their normal routines disrupted and feeling they were neglecting other obligations. Respondents with another adult to support them experience less disruptions and less financial burden.

The data do suggest that parents are the most accommodating, especially when the former patient's behavior is judged "abnormal." One might argue that parents are re-assuming their normal roles. Fewer parental families perceive themselves neglecting other responsibilities. The parental role is, of course, a role that accepts dependency and responsibility for others much more so than the role of spouse or of distant relative. Interestingly, the more distant family relationships, ones lacking a marital or parental bond with the former patient, suffered the least financial burden but greater disruptions in their perceived role and family routines. Apparently, for them, the former patient is not a deficit, just troublesome.

In sum, the presence of clincially disturbed behavior seems to be a pervasive force behind families' objective burdens. Nevertheless, the extent of families' reporting disruptions and burdens seems to be markedly influenced by family composition. Family respondents who have another person present, especially another adult to serve as a backup, experience fewer household and role disruptions.

Discussion

The return of the mentally ill relative to the home does exact a price from the family. To some extent, it seems reasonable to argue that those families with the least interpersonal resources pay the highest price of all.

Social supports do seem to have an affect on the fact and the feeling of disruption. Although the presence of disturbed behavior clearly compounds the disruption wherever it is, how much this behavior disrupts and the ways in which it is reacted to seem somewhat amenable to the influence of other people. The ameliorative quality of social supports in the presence of disruptive behavior, which is an axiom of sociological thought, suggests that the burden phenomenon is something of a situational emergent. While most families will experience burden of some sort and to some degree as a result of the mere presence of a mentally ill relative, it is not a necessary accompaniment to the patient's return home. Recall, none of the respondents whose spouses were relatively symptom-free reported an objective burden of disrupted everyday routines.

Clearly, some sort of familial burden can be expected, but the kind and its intensity are most likely to arise in response to a specific constellation of psychiatric and familial arrangements. Being home and being symptom-free is not likely to be an objective burden to one's family. Being home with symptoms is most likely to be an objective burden. Coping with a formally hospitalized relative alone, or without another adult to share the troubles, make the objective

burdens and the family's affective burden more probable. While lack of supports seems to exasperate the objective burdens and the family's feelings of being burdened, it seems to ease the sense of embarrassment.

We should note that roughly 15 percent of the families experienced either objective or subjective burden even when there were no symptoms present to bring about the burden. This would suggest that the notion of burden flows from more than problematic, clinical behavior. Here questions of the role of the "mental patient" label and identity, and the family's tolerance for any type of accommodation ought to be asked.

Finally, of all relatives, parents seem to be most tolerant of the patient's post-hospital situation. Though here, too, there are often heavy costs, especially in terms of the emotional strain. Spouses and more distant relatives are about equally likely to react adversely if the formerly hospitalized patient's behavior is symptomatic, but spouses are less likely to react adversely if his behavior is relatively symptom-free. It could be that spouses perceive themselves as not having bargained for this type of sick-care responsibility.

Conclusions

A quarter century ago, Parsons and Fox (1952) argued that the American family could not tolerate the strain of caring for the long-term disabled family member. Later, Vincent (1967:30) issued a similar warning: "how will the family be affected by the return of the mentally ill member?" The move toward a community-centered mental health

delivery system becomes, in many respects, a natural, nation-wide experiment to test the Parsons-Fox hypothesis and to answer Vincent's question.

Our findings suggest that the strains Parsons and Fox warned of are there, silently corroding the stability of these families. These silent forces deserve more of our attention. Under what conditions does objective burden become subjectively felt as a familial difficulty? What is the feedback effect to the patient's post-hospital adjustment when he remains in a household where his presence is perceived as destructive? If some families seem structurally predisposed to being overloaded and reveal nothing but utter hopelessness, deep despair and unmitigated pain, what are the short-term consequences for the family unit and the long-term consequences for both individual family members and larger social system?

To date, families coping with the policies for deinstitutionalization and the long-term care of psychiatrically disabled relatives are probably the least organized and vocal of all groups affected by the changes in the mental health delivery system. By neglecting the silent, pervasive strains now "invading" many families, we not only threaten the quality of family life with an anti-family bias, but we deny ourselves the fairest test of our new solutions to the problems of mental health. After all, if the community mental health experiment is to fail, it should do so for the right reasons.

FOOTNOTES

[1] In this article, following a recommendation of Bachrach (1976), the term "deinstitutionalization" refers to a process involving two elements: (1) the eschewal, shunning or avoidance of traditional settings, primarily state hospitals, for the care of the mentally ill; and (2) the concurrent expansion of community-based services for the treatment of these individuals.

[2] Following Bachrach's recommendation (1976), the terms "patient," "former patient," and "mentally ill relative" are employed in this article to refer to those individuals who are, have been or might have been, but for the deinstitutionalization movement, on the rolls of long term mental institutions, especially state hospitals.

[3] For a thorough review of the literature on families' reaction to the former patient return home, see Kreisman and Joy (1974).

[4] "Patients" are included in this study were persons whose primary diagnosis was neither organic or alcohol/drug addition.

[5] Deviant behavior may not be assumed to be an indicator of burden, yet deviant behavior could itself be a reaction to the family's reaction. That is, while we have assumed deviant behavior to be clinically syptomatic behavior leading to the family's reaction, it could be defensive behavior resulting from the family's reaction to the fact of the mentally ill member's sheer presence.

[6] We recognize that the three family composition variables--household size, type of familial bond, and the presence of adult supports--are conceptually distinct, but empirically are highly correlated with each other. It is for this reason that we choose not to use a multivariant statistic in our data analysis.

Table 1

Demographic Characteristics of the Sample (N= 125)

Item	N	%
Sex		
Male	42	34
Female	83	66
Age		
≤35 years	19	15
36-55 years	59	47
56+ years	47	38
Race		
White	72	58
Black	53	42
Education		
≤High School Graduate	60	49
High School Graduate	43	35
Some College	19	16
Marital Status		
Single	9	7
Married	85	68
Divorced or Separated	31	25
Socioeconomic Status*		
I, II	10	8
III	16	13
IV	36	31
V	54	44
Unknown	9	4
Relationship to Former Patient		
Spouse	43	34
Parent	52	42
Other Relative (sibling, child, in-law)	30	24
Patient's Sex		
Male	58	46
Female	67	54
Patient's Age		
≤35 years	60	48
36-55 years	50	40
56+ years	15	12

*Measured by the Hollingshead Two-Factor Index of Social Class

Table 2

Percent of Family Respondents Reporting Burden

by Patient's Psychiatric Symptoms Level

Measures of Burden	Total Sample (N= 125)	Low Symptoms (N= 78)	High Symptoms (N= 47)	p *
Objective Burden				
Financial Burden	38	27	58	<.01
Neglects Responsibilities	33	17	61	<.01
Normal Routines Disrupted	31	9	67	<.01
Subjective Burden				
Shame	46	35	64	<.01
Sense of Burden	77	71	88	<.01
Some	62	62	62	
Severe	15	9	26	

*p is based on chi-square statistic

Table 3

Percent of Family Respondents Reporting Subjective Burden

by Patient's Psychiatric Symptom Level and Family Composition

Family Composition Variables	Shame			Sense of Burden		
	Symptoms			Symptoms		
	Low (N= 78)	High (N= 47)	p*	Low (N= 78)	High (N= 47)	p
Household Size						
Alone	29	69	<.05	67	100	<.01
Small	37	61	NS	80	83	NS
Large	37	64	NS	63	82	NS
Adult Supports						
No	28	70	<.01	61	96	<.01
Yes	41	58	NS	72	79	NS
Family Type						
Conjugal	19	69	<.01	58	88	<.01
Parental	38	60	NS	72	90	NS
Other	53	64	NS	84	82	NS

*p is based on chi-square statistic

Table 4

Percent of Family Respondents Reporting Objective Burden

by Patient's Psychiatric Symptoms Level and Family Composition

Family Composition	Financial Burden			Neglects Responsibilities			Routines Disrupted		
	Symptoms			Symptoms			Symptoms		
	Low (N= 78)	High (N= 47)	p*	Low (N= 78)	High (N= 47)	p	Low (N= 78)	High (N= 47)	p
Household Size									
Alone	38	54	NS	12	73	<.01	19	92	<.01
Small	14	51	<.01	14	55	<.01	7	52	<.01
Large	33	60	NS	22	60	NS	4	70	<.01
Adult Supports									
No	36	64	NS	21	70	<.01	10	76	<.01
Yes	18	52	<.05	13	52	<.01	8	58	<.01
Family Type									
Conjugal	23	75	<.01	13	67	<.01	0	62	<.01
Parental	28	50	NS	13	47	<.05	10	60	<.01
Other	28	44	NS	29	78	<.05	22	89	<.01

*p is based on chi-square statistic

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